

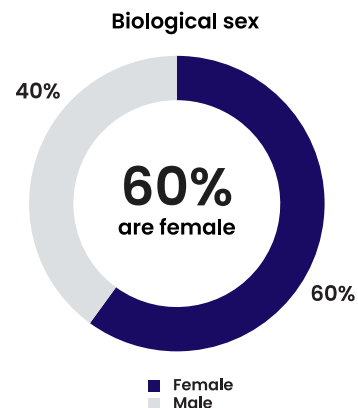
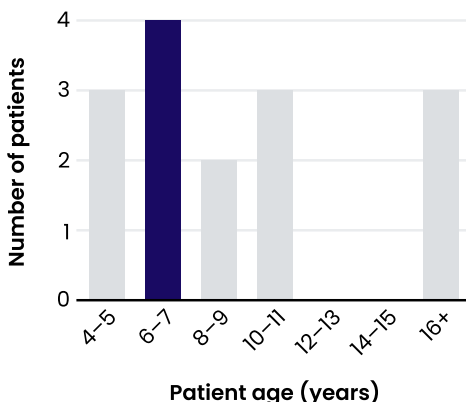


15 patients included in the study

Data is from the AllStripes SURFI research cohort of 23. Fifteen of these patients were included in the study. The data below represent information abstracted from medical records by the AllStripes Abstraction Team and analyzed by the AllStripes Research Team.

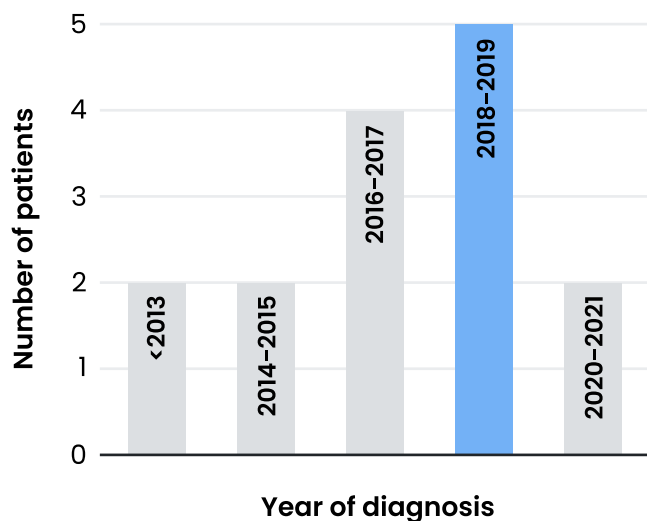
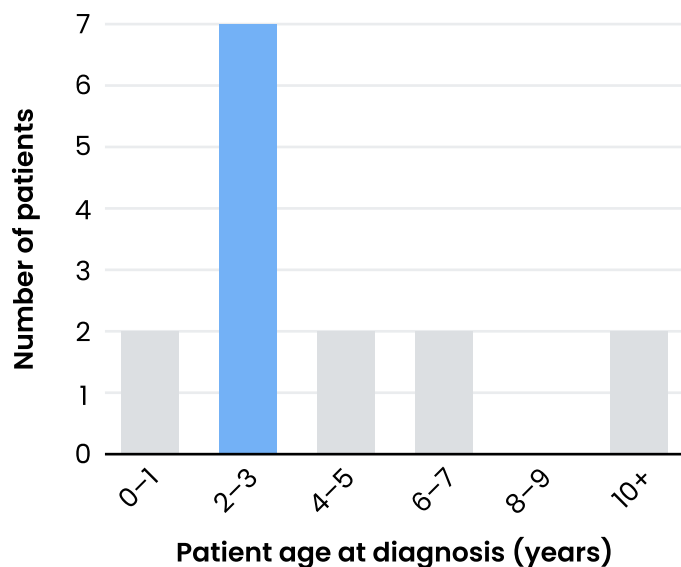
Cohort demographics

Characteristic	N = 15
Biological sex	
Female	9 (60%)
Male	6 (40%)
Median age	7
Country	
US	15(100%)



- The SURFI cohort described here comprises 15 patients
- The cohort is **mostly female (60%)** with a **median age of 7 years old**

Diagnosis

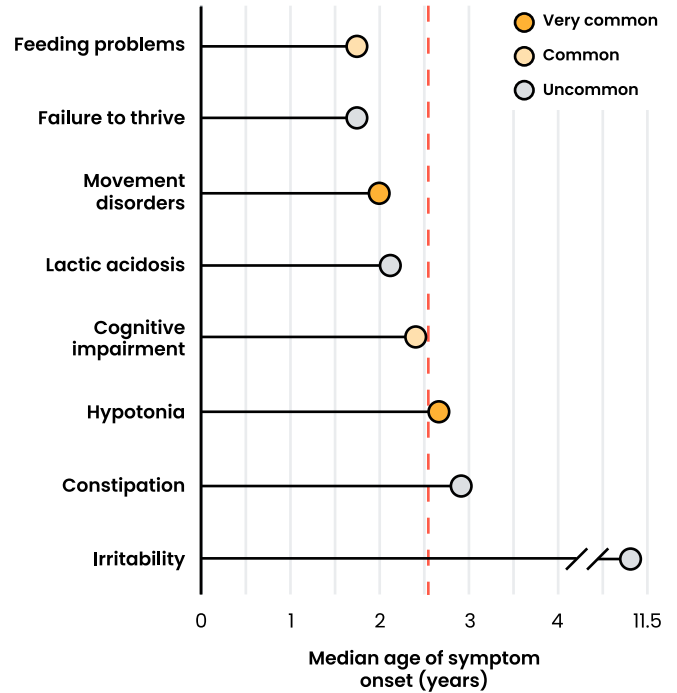
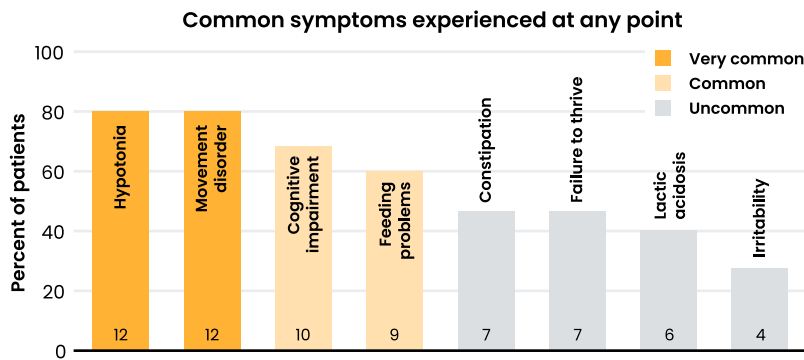
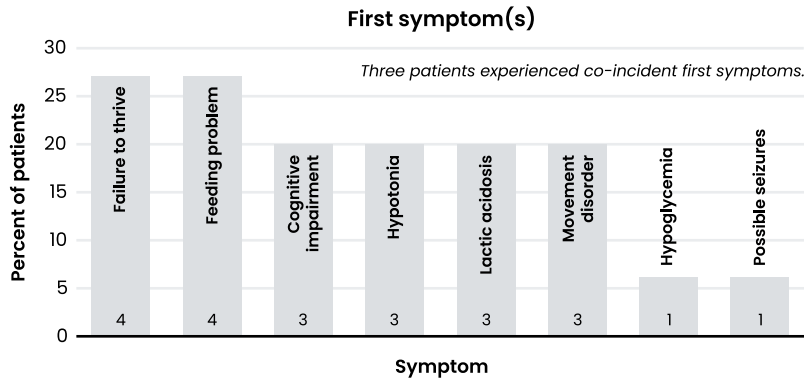


- Patients were diagnosed between the ages of 1 month - 13.5 years, and the **median age at diagnosis was 2.5 years**
- All patients were diagnosed in 2008 and later. The most patients were diagnosed between 2018 and 2019.



AllStripes would like to thank **Cure Mito Foundation** and **MitoAction** for their partnership in growing this research community. AllStripes would also like to thank the patients, families and caregivers who have generously contributed data.

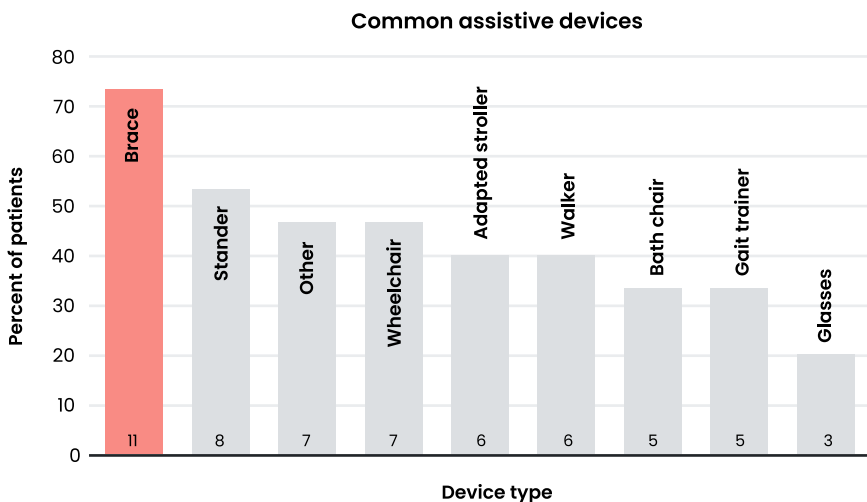
Symptoms



Not all patients experience all symptoms listed here. Please reference the legend for symptom rarity.

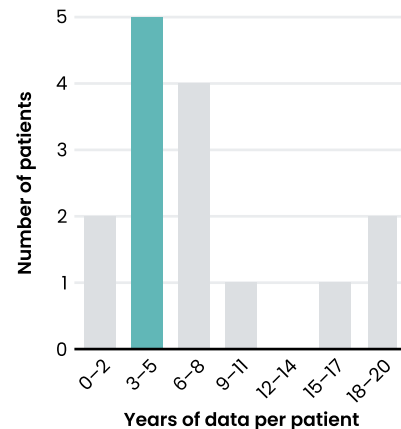
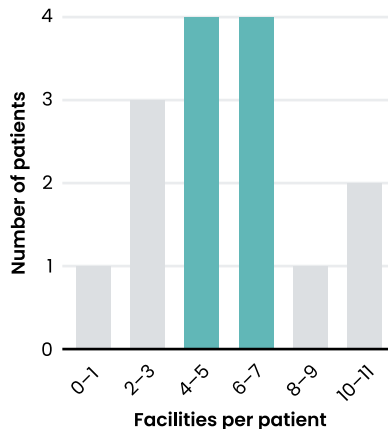
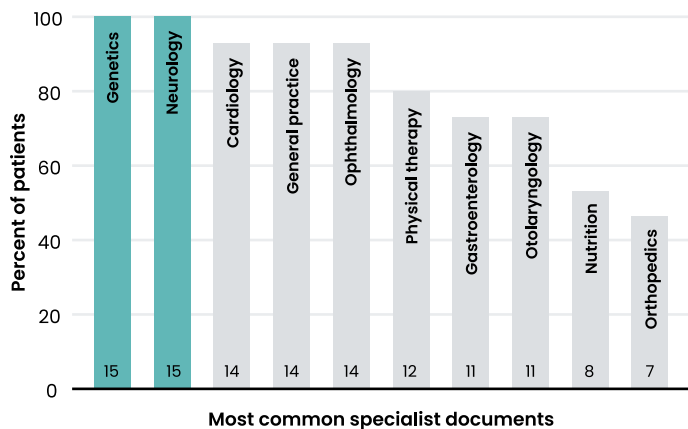
- The median age at first **symptom onset** was 1.4 years
- The most common first symptoms were failure to thrive (27%) and feeding problems (27%)
- **Hypotonia (low muscle tone) and movement disorders were experienced by 80% of patients in the cohort**
- **Feeding problems** (21 months) and **failure to thrive** (21 months) had the earliest median ages of symptom onset and both preceded the median age of diagnosis (30 months)
- Very common symptoms were experienced by 75% of patients or more, common symptoms were experienced by 50-74% of patients, and uncommon symptoms were experienced by 25-49% of patients

Assistive devices



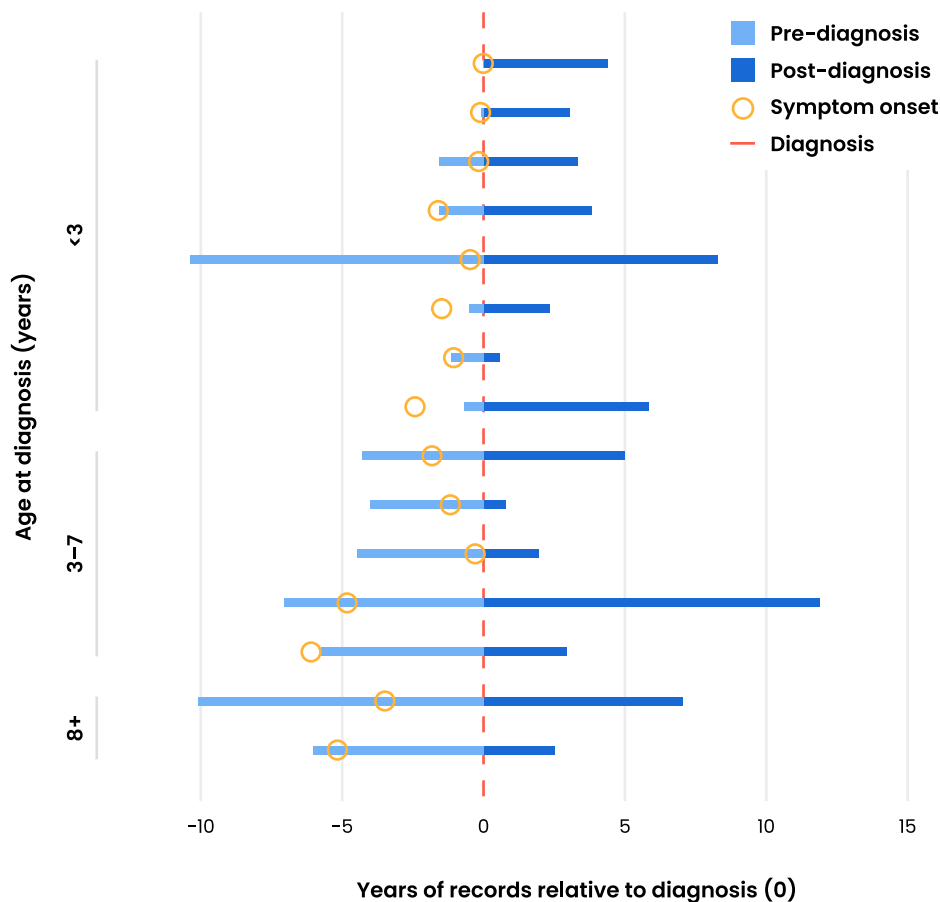
- These data represent assistive devices mentioned in the medical records
- **Brace devices were the most common (73%)**
- Of brace-type devices, ankle foot orthoses were the most common (53% of all patients)
- **All 15 patients used an assistive device**
- Patients used a **median of seven different assistive devices** over their records
- "Other" assistive devices include a wide range of devices from communication devices, seating systems and positioning devices, feeding devices, and more.

Management



- In total, we gathered **3,773 medical records across the 15 patients** included in this study - a **median of 220 records per patient**
- All patients had records from **genetics and neurology**
- Patients in this cohort had records from a **median of 5 facilities**
- The median number of years represented by the records for each patient was **6.4 years**

Overall journey



- Each horizontal line represents the record span of one patient
- The grey bars at the left of the graph indicate age at diagnosis
- The light blue line to the left of zero indicates the length of records before diagnosis, while the darker blue line to the right of zero indicates the length of records after diagnosis
- The open yellow circles indicate the time of symptom onset relative to diagnosis
- The **median length of time covered by records before diagnosis is 4.0 years**
- The **median length of time covered by records after diagnosis is 3.3 years**

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